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Impact of Perceived Stigma on Inflammatory Bowel Disease Patient Outcomes

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Abstract

Background—Perceived stigma has been linked to disease outcome in several chronic illnesses. Stigmatization of illness often leads to increased psychological distress and poorer quality of life. While body stigma has been identified as a specific inflammatory bowel disease (IBD) patient concern, no study to date has systematically investigated the presence of stigma in IBD or its effects on disease course and management.

Methods—Participants were recruited online and through the Illinois chapter of the Crohn's & Colitis Foundation of America. A screening measure was used to identify an established IBD diagnosis. Patients completed the Perceived Stigma Scale in IBS, Inflammatory Bowel Disease Questionnaire, Rosenberg Self-Esteem Scale, General Self-Efficacy Scale, the Brief Symptom Inventory, and the Rating Form of IBD Patient Concerns.

Results—A total of 211 patients (156 CD, 55 UC) with a confirmed diagnosis for a minimum of 6 months completed the study. Eighty-four percent of participants reported perceived stigma. Hierarchical regression demonstrated that perceived stigma accounted for 10%–22% of the variance in health-related quality of life scores, 4%–16% for psychological distress, 5% for medication adherence, 19% for self-esteem, and 8% for self-efficacy. Effect sizes were small, but comparable with more traditionally evaluated patient variables.

Conclusions—The majority of IBD patients report some perceived stigmatization. These results suggest that perceived stigma is a significant predictor of poorer outcomes in patients with IBD when controlling for illness and demographic variables. Perceived stigma is a potentially important psychosocial factor in IBD patient care and warrants further investigation.

Keywords

perceived stigma; quality of life in IBD; compliance issues in IBD; psychosocial aspects of IBD

The inflammatory bowel diseases (IBDs), including ulcerative colitis (UC) and Crohn's disease (CD) are life-long, concealable illnesses that usually begin at a young age and are associated with significant burden from symptoms and/or treatments.¹ These disease characteristics make IBD susceptible to stigma.² Stigma is defined as the societal labeling of an individual as abnormal, and has been identified as an important construct in outcomes for chronic illnesses.^{3–6} In addition to its concealability, symptom burden, and limited treatment options, IBD is at risk for stigmatization because of the nature of symptoms focused around the bowel and

rectum, its relatively unalterable course, and its historical background as a psychosomatic illness among lay people.⁷

While the IBD literature has not, to our knowledge, measured stigma as an independent construct, patients with IBD do voice several stigma-related concerns, including being treated as different, having an ostomy bag, and being a burden on others.^{8–10} These concerns occur cross-culturally¹¹ and little is known about the impact of perceived stigma on disease outcomes and patient experience. Stigma research from other chronic illnesses^{12–15} supports the idea that stress associated with perceived illness stigma may worsen the clinical course of IBD, lead to poorer outcomes, increase the risk of developing other stress-related illnesses,¹⁶ contribute to relapse or worsening of IBD symptoms, reduce treatment adherence,^{17,18} increase psychological distress, and lead to poorer quality of life.

We conducted an exploratory study to identify the role and impact of perceived stigma in IBD. We hypothesized that perceived stigma 1) exists among IBD patients; 2) is mediated by illness characteristics such as severity, duration, and remission status; and 3) correlates with outcomes of health-related quality of life (HRQOL) and medication adherence.

MATERIALS AND METHODS

Study Design

This study used a cross-sectional correlational research design. Participants were recruited via targeted mailing or email through the Illinois Chapter of the Crohn's & Colitis Foundation of America (CCFA), or online via high-traffic IBD message boards (www.healingwell.com, www.ibdsucks.org, www.crohnszone.co.uk), classifieds (www.craigslist.com), and social psychology research websites (www.onlinepsychresearch.co.uk, <http://psych.hanover.edu/Research/exponent.html>). The Web-based questionnaire was designed using the secure third-party survey provider Survey Monkey (www.surveymonkey.com) and embedded in a custom HTML web-site introducing the study to participants. After obtaining informed consent, all participants then completed a set of questionnaires.

Participants

A total of 211 participants (156 CD, 55 UC) with a self-reported diagnosis of CD or UC for a minimum of 6 months completed the study between August and October of 2007. Participants were grouped by recruitment source: CCFA direct mail, Online Message Board, and Other Online, which included email, classifieds, research Websites, and search engine hits. For the direct mailing, 50 packets were returned for a 10% response rate. Four packets did not include signed informed consent and were excluded from analysis. Via online recruitment, 206 people began the study and 2 declined informed consent. The online completion rate was 80%. Overall, 153 online participants were from support message boards, 17 were emailed the study, 13 were from classifieds, 8 were from search engine hits, and 6 were from research sites.

Measures

HRQOL—The Inflammatory Bowel Disease Questionnaire (IBDQ¹⁹) is a well-established, disease-specific, 32-item outcome measure that assesses HRQOL in IBD patients. Questions are grouped into 4 domains: gastrointestinal symptoms, systemic symptoms, emotional functioning, and social functioning. IBDQ scores reflect both IBD symptom severity and quality of life.^{19,20}

Treatment Adherence—The Medication Taking Behavior Scale (MTBS) was used to measure adherence over the last 2 weeks.²¹ The MTBS is a 4-item self-report measure assessing

forgetting to take medication, being careless about taking medication, or intentionally stopping medication and has been used in various medical settings to evaluate medication adherence.

Self-Esteem and Perceived Self-Efficacy—The Rosenberg Self-Esteem Scale (RSES) was used to measure self-esteem²² and the General Self-Efficacy Scale (GSE) was used to measure perceived self-efficacy.²³

Psychological Distress—The Brief Symptom Inventory-18 (BSI)²⁴ is an 18-item questionnaire to assess overall psychological distress, symptom intensity, and total number of symptoms reported. The questions yield a global score and 3 symptom dimensions: somatization, depression, and anxiety. Higher scores indicate higher levels of distress.

Measurement of Perceived Stigma—Participants also completed the Perceived Stigma Scale in IBS (PSS-IBS)²⁵ as part of our goal to validate this measure in the IBD population and to determine the presence of perceived stigma. The PSS-IBS is a 10-item questionnaire designed to measure perceived stigma in irritable bowel syndrome patients that focuses on disclosure, attitudes and knowledge about IBS, illness validity, seriousness, and blame. These items are evaluated for family members, spouse, friends, employer/supervisor, and coworkers/classmates. Higher scores indicate greater levels of perceived stigma. Preliminary findings suggest that the PSS-IBS is a valid and reliable measure of patient-perceived stigma. For this study, the term “IBS” was replaced with “IBD” (i.e., “My IBD symptoms are not taken seriously by...,” “When some people know about my IBD symptoms they treat me differently, including...”). The PSS-IBS demonstrated good reliability (Cronbach’s $\alpha < 0.89$; mean inter-item reliability = 0.89; Guttman split half reliability = 0.87) and validity ($r = 0.25$, $P < 0.01$ with Body Stigma Scale of RFIPC) in this sample (see Appendix).

The Rating Form of IBD Patient Concerns (RFIPC) was also used to determine the degree of “body stigma” participants reported, both as a correlate to the PSS-IBS and specific stigma measure. The RFIPC is a 25-item questionnaire to assess concerns and worries associated with IBD and its treatment.⁸ Questions yield 4 domains: impact of disease, sexual intimacy, complications of disease, and body stigma. Higher scores equate to greater levels of concern. Validation studies have found the RFIPC to be a valid, reliable, and consistent measure.⁸

Sociodemographic and Clinical Information—Participants were asked to report the following variables: age, gender, ethnicity, education level, population of hometown, marital status, IBD diagnosis, disease duration, remission status, extraintestinal manifestations, date of most recent disease flare, flare frequency and intensity, medication regimen, frequency of physician appointments, surgical history, and presence of an ostomy. Illness severity variables included: remission status, extraintestinal manifestations, having a flare in the past year, flare frequency, and flare intensity.

Statistical Analysis

All statistical analyses were done using SPSS 16.0 for Windows (Chicago, IL). Statistical significance was set at $P \leq 0.05$ for all analyses. Power analyses were conducted for multivariate tests, with a minimum power requirement for significance set at ≥ 0.80 . Preliminary descriptive statistics were completed where applicable. A series of Pearson chi square analyses, independent samples *t*-tests, and 1-way analyses of variance (ANOVAs) were performed to evaluate significant differences between CD and UC for demographic and illness characteristics.

To determine control variables for understanding the effect of stigma on dependent variables, demographic and illness variables were evaluated further for significant differences in HRQOL

and psychological distress using multivariate analyses of variance (MANOVAs). Univariate analysis of variance was used to evaluate these variables for medication adherence.

Three separate hierarchical regression analyses were performed to test the influence of stigma on HRQOL, psychological distress, and medication adherence. Any significant variables identified via MANOVA were entered in Step 1 of the regression analyses as control variables. The stigma variables for total score on the PSS-IBS and the subscale score for body stigma on the RFIPC were entered in Step 2. Casewise diagnostics were performed to evaluate for significant outliers, which were excluded from analysis.

For HRQOL the criterion variables were the subscale scores for bowel symptoms, systemic symptoms, emotional functioning, and social functioning. The BSI-18 subscale scores for depression, anxiety, and somatization were the criterion variables for the second regression analysis evaluating the impact of stigma on psychological distress. The total score on the MTBS served as the criterion variable for medication adherence.

Effect sizes were calculated separately for the PSS-IBS and the body stigma scale of the RFIPC and evaluated using Cohen's criteria.²⁶

Ethical Considerations

Any individually identifiable data were removed to ensure participants' privacy. This study was reviewed and approved by the ethical board for each institution involved.

RESULTS

Our sample mirrors other IBD survey samples^{8,27} in terms of demographics and clinical characteristics (Table 1). In all, 77% were female, 97% were White, 69% were under age 46, and 49% were college educated; 43% were diagnosed with IBD within the last 5 years and 53% were in remission. No significant demographic differences were found between UC and CD participants for recruitment source, age, gender, marital status, ethnicity, city size, or education level.

There were no significant differences for remission status, having a flare in the past year, the average length of flare, or flare frequency and severity. Congruent with previous IBD research,²⁷ CD participants were more likely to report having extraintestinal symptoms (χ^2 (1, $N = 211$) = 8.85, $P = 0.004$), although no significant differences appeared among the type of extraintestinal symptoms when evaluating only those participants who reported their presence. CD participants were also more likely to have a fistula (χ^2 (1, $N = 211$) = 9.82, $P = 0.002$) and be polysymptomatic (χ^2 (1, $N = 211$) = 8.85, $P = 0.004$); that is, have greater than 1 extraintestinal symptom and/or have a fistula and at least 1 extraintestinal symptom.

Overall, treatment regimens were similar between UC and CD, with no significant differences existing for those not taking medication to treat their IBD, steroid use or dependence, the number of pills taken per day, or frequency of physician appointments. Participants with UC were more likely to take medication 2 or more times per day as compared to CD (χ^2 (5, $N = 211$) = 13.35, $P = 0.02$). Participants with CD were significantly more likely to have had surgery (χ^2 (1, $N = 211$) = 40.21, $P = 0.000$) and have an ostomy (χ^2 (1, $N = 211$) = 3.47, $P = 0.05$), although no significant differences existed for the number of surgeries had between diagnostic groups. For treatment adherence, CD and UC participants reported no significant differences in the number of canceled physician appointments over the last year, or nonadherence in the past 2 weeks or past year.

Determining the Sample for Analysis

The means and standard errors of measure (SEM) for the HRQOL, psychological distress, and adherence scales are included in Table 2. No differences were seen between CD and UC participants for total score, bowel symptoms, emotional functioning, and social functioning on the IBDQ. Participants with CD reported lower scores for systemic symptoms ($t(209) = -2.15$, $P = 0.033$) on the IBDQ. No significant differences were reported between diagnostic groups for treatment nonadherence in the past 2 weeks, psychological distress, perceived stigmatization, patient concerns, self-esteem, or self-efficacy.

Differences in the dependent variables HRQOL and psychological distress were evaluated by diagnosis to determine if CD and UC should be evaluated separately versus combined as 1 group. Wilks' criterion analysis revealed that there was no multivariate main effects for disease type for subscale scores on the IBDQ ($P = 0.06$), the BSI-18 ($P = 0.76$), or the RFIPC ($P = 0.47$). Therefore, all 211 participants were grouped for subsequent analyses for the effect of perceived stigma on these dependent variables.

Rates of Perceived Stigma in IBD

To determine the presence of perceived stigma, scores on the PSS-IBS were evaluated. Eighty-four percent of participants reported perceived stigma, with most reporting low to moderate levels (Table 3). Fourteen percent reported feeling moderately stigmatized by family, 23% by friends, and 11% by spouse or significant other. Twenty percent of participants reported feeling moderate stigmatization from medical providers; moderate perceived stigma was also present in the workplace, among co-workers (28%), and employers (32%).

Effects of Patient Characteristics on Perceived Stigma

To evaluate the role of perceived stigma in patient outcomes, MANOVAs were first performed to identify control variables from demographic and illness characteristics. Analysis of HRQOL revealed that there were multivariate main effects for several illness severity variables, including remission status, having a flare in the past year, flare duration, and having extraintestinal symptoms (all $P < 0.05$). For psychological distress, multivariate main effects were seen for recruitment source, marital status, remission status, having a flare in the past year, flare frequency, and having extraintestinal symptoms (all $P < 0.05$). Post-hoc analysis identified the subscales of the IBDQ and BSI-18 that were influenced by these variables, which were then controlled for in Step 1 of subsequent hierarchical regression analyses.

Perceived Stigma and IBD Patient Outcomes

To understand the relationship between stigma and HRQOL, a hierarchical linear regression analysis was performed. To test for the presence of multicollinearity, variance inflation factor (VIF) values less than 10, and tolerance values greater than 0.10 were considered indicators of no multicollinearity between variables. No violations of this assumption occurred for any of the regression analyses performed.

HRQOL

Significant effects were obtained for perceived stigma on all 4 subscale models of the IBDQ after controlling for identified illness severity and demographic variables. For bowel symptoms ($F(3,3991) = 49.42$, $P < 0.001$), perceived stigma accounted for 10% of the variance, for systemic symptoms ($F(6,726) = 24.38$, $P < 0.001$) 13% of the variance, for emotional functioning ($F(3,6550) = 43.57$, $P < 0.001$) 22% of the total variance, and for social functioning ($F(5,1211) = 31.68$, $P < 0.001$) 9% of the total variance in scores. Effect sizes (PSS-IBS, RFIPC) were small, with the largest effect found for emotional functioning (partial $r^2 = 0.10$,

0.14), followed by systemic symptoms (0.08, 0.10), bowel symptoms (0.04, 0.10), and social functioning (0.03, 0.10).

Psychosocial Distress

Perceived stigma significantly predicted somatization ($F(8,119) = 9.69, P < 0.001$), depression ($F(4,361) = 17.25, P < 0.001$), and anxiety ($F(4,219) = 15.8, P < 0.001$) as measured by the BSI-18. Perceived stigma accounted for 4% of the total variance for somatization, 15% of the total variance for depression, and 16% of the total variance for anxiety scores when controlling for demographic and clinical variables identified via previous multivariate analysis. Effect sizes were again small, with the largest effect for stigma on anxiety (partial $r^2 = 0.13, 0.07$), then depression (0.10, 0.07) and somatization (0.02, 0.03).

Treatment Adherence

Since no significant main effects were found for demographic or clinical variables and treatment adherence, a simple linear regression was performed to evaluate the effect of perceived stigma on adherence. The model was significant ($F(205) = 4.96, P = 0.008$), with perceived stigma accounting for 5% of the total variance in medication adherence in the past 2 weeks. The effect size was small when using the PSS-IBS (partial $r^2 = 0.05$), but essentially zero for the RFIPC body stigma scale.

Self-Esteem and Self-Efficacy

Simple linear regression was also performed for self-esteem and self-efficacy. The model for both self-esteem ($F(2,636) = 23.91, P < 0.001$) and self-efficacy ($F(2,223) = 9.04, P < 0.001$) were significant. Perceived stigma accounted for 19% of the total variance for self-esteem and 8% of the total variance for self-efficacy scores. Effect sizes were small for self-esteem (partial $r^2 = 0.04, 0.14$), and for self-efficacy (0.03, 0.05).

DISCUSSION

The results of the current study suggest that perceived stigma exists among individuals with IBD with similar deleterious effects as in HIV/AIDS, mental illness, and psoriasis.^{3,5,13,16} No significant differences were found between CD and UC, suggesting that perceived stigma is associated with the IBD diagnosis and/or its symptom pattern as a whole. Surprisingly, no significant differences were found for levels of perceived stigma reported between individuals who were in remission and those who were currently experiencing a disease flare-up. This suggests that the presence of symptoms alone does not fully explain individuals reporting feeling stigmatized by others because of their illness, and that perceived stigma might be an enduring factor for IBD patients regardless of flare status. Also, due to the often-cyclical nature of IBD disease activity, anticipation of a future flare may be sufficient in increasing or maintaining levels of perceived stigmatization.

As expected, individuals who reported greater frequency of disease flare-ups also reported greater levels of perceived stigma. Because perceived stigma appears to be independent of remission status, individuals who report more frequent flares may be seen as having more severe disease, have more obvious impairment, and therefore be more prone to stigmatization by others. For example, a patient with a complicated IBD may be more limited in their ability to go out in public due to chronic diarrhea or pain that in turn reduces their social value to others. Eye inflammation or skin rashes that others may interpret as infectious or contagious may also limit their interaction with others. Patients may also lose a promotion at work because of complaints from colleagues about the amount of sick-time they take. Duration of illness was positively correlated with levels of perceived stigma. Past research has shown that individuals who are perceived as being more severely ill, or those with degenerative or unalterable disease

courses tend to have the highest levels of stigma.⁷ Disease complexity was also a significant factor in reported perceived stigma in IBD, with individuals who reported being polysymptomatic being more likely to report greater levels of perceived stigma.

Once the presence of perceived stigma was established, the next step was to evaluate the role stigma might have in relevant patient outcomes, including treatment adherence and HRQOL. We found that perceived stigma was a significant predictor of poorer HRQOL among individuals with IBD. This finding is similar to previous chronic illness stigma literature.^{3, 12–15,28,29} Perceived stigma was a significant predictor of increased anxiety and depression, as well as decreased self-esteem and self-efficacy. By increasing levels of depression and anxiety, perceived stigma may also compromise immune system functioning and lead to more frequent disease exacerbations due to increases in proinflammatory cytokines.³⁰ Future prospective studies would clarify the relationship between stigma and psychological functioning while evaluating the physiological impact of stigma on IBD.

Greater perceived stigma was also a significant predictor of decreased medication adherence in the past 2 weeks. Increased perceived stigmatization may heighten a person's sense of internalized shame or sense of loss of self, which may reduce their motivation to maintain their health. In addition, because IBD is a concealable illness, concerns about unplanned illness disclosure associated with medication regimens may affect adherence. Because life-long medication regimens are common for IBD patients and necessary to control disease symptoms, reduced medication adherence due to perceived stigmatization can potentially lead to reduced physical functioning, reduced HRQOL, and increased psychological distress. Decreased adherence may also be related to increased depression and lack of social support. Many of the participants were recruited from online support message boards, which may indicate a lack of social support beyond the World-Wide Web.³¹

Generally, perceived stigma effect sizes were small for all outcome variables. While Cohen²⁶ suggests that most psychological research effect sizes are below 0.30, Glass et al³² caution that the interpretation of effect sizes as “small, medium, or large” should only be done in the context of related research. With these limitations in mind, it is better to interpret the effect sizes reported in this study by comparing how strong of an effect stigma had on outcomes relative to other control variables. When evaluating stigma in this context, its effect sizes for HRQOL and psychological distress were comparable to flare frequency and duration, having a flare in the past year, or having extraintestinal symptoms. While statistically the effect size was defined as small, perceived stigma was as large of an influence on HRQOL as other more traditionally evaluated illness characteristics. Effect sizes for medication adherence, self-esteem, and self-efficacy were comparable to those reported for HRQOL and psychological distress, indicating consistency in the size of the effect that perceived stigma has on various patient outcomes.

Since the nature of chronic illness stigma is complex and part of a broader integrated model of biopsychosocial influences on patient outcomes, it is not surprising that its effect is relatively small by definition. However, since perceived stigma may have similar effects on important patient outcomes as more traditionally measured clinical constructs, it is recommended that clinicians be aware of the potential influence of perceived stigma and incorporate this into IBD patient evaluation.

There are several limitations to this study. This study used a cross-sectional, nonexperimental design. It may be that levels of perceived stigma and its subsequent effects vacillate over time, depending on a variety of social, illness, or personal factors. A repeated-measures or longitudinal design would provide better understanding of the enduring effects of perceived stigma in IBD. This study also did not utilize a comparison control group to rule out other

possible explanations for reported perceived stigmatization. The present study also utilized the Internet, including support message boards, for recruitment. The majority of the participants (75%) in this study were recruited online, which may pose significant bias in this sample. Internet access among individuals with IBD has been reported to be as high as 81%,³³ and IBD patients are likely to use the Internet to find information about their disease. While the Internet is increasingly being used as a source of recruitment, recent research has shown that significant differences in psychosocial adjustment are present between clinical and Internet populations among individuals with gastrointestinal illness, including IBD.³⁴ Significant differences between Internet and non-Internet participants were controlled for during analysis. However, the study sample as a whole may be more likely to report perceived stigma than clinical populations. To better understand these potential differences, future studies should incorporate a more even distribution of online, clinical, and general population participants.

As previously mentioned, the study sample was almost entirely Caucasian. The results of this study should be interpreted with caution when evaluating African American, Hispanic, or other ethnic minority clients. Additionally, the current sample was skewed so that more females completed the study. While very recent research shows that CD is more common among women, the present sample had a greater proportion of women than has been found in past research.

This study also utilized self-report measures, including retrospective reports of medication adherence. While the study was anonymous, there is always a chance that self-report, especially of more sensitive topics, may be biased toward the positive. This may be reflected in this study's finding of no significant differences between clinical and demographic variables for medication adherence. Previous research has shown that several factors, including being symptomatic, psychological distress, and undergoing long-term treatment, are related to medication adherence.^{17,21} Future research utilizing chart review to identify missed physician appointments or medication nonadherence would be more accurate measures of the influence of perceived stigma on illness treatment adherence.

CONCLUSIONS

In this study the majority of IBD patients reported perceived stigmatization, which in turn was a significant predictor of poorer outcome, even after controlling for illness and demographic variables. We provided preliminary yet compelling evidence that the presence of IBD-related stigma is associated with poorer quality of life, psychological adjustment, self-concept, and treatment adherence. Individuals with more complex symptoms or frequent disease exacerbations may be at the greatest risk for experiencing perceived stigma. Finally, perceived stigma appears to be consistent regardless of remission status and may be a relatively stable illness construct.

Perceived stigma is a potentially important psychosocial factor in IBD patient care and warrants further investigation. Because stigma involves psychological and social factors, several potential points of intervention are possible to lessen the impact of stigma on individuals with IBD.

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TABLE 1
Sociodemographic and Clinical Characteristics by IBD Type

Characteristic, n (%)	CD (n=156)	UC (n=55)	Total Sample (N=211)	P
Female gender	122 (78)	43 (78)	165 (78)	0.57
Age				0.35
18–29	30 (19)	15 (27)	45 (21)	
30–45	73 (47)	23 (42)	96 (46)	
46–55	31 (20)	13 (24)	44 (21)	
56–70	15 (10)	4 (7)	19 (9)	
70–75	7 (4)		7 (4)	
Ethnicity				0.30
Caucasian	152 (98)	53 (96)	205 (97)	
African-American	2 (1)	1 (2)	2 (1)	
Asian/Pacific Islander	2 (1)	1 (2)	3 (2)	
Hometown population				0.61
Large	65 (42)	29 (53)	94 (45)	
Medium	56 (36)	18 (33)	74 (35)	
Small	19 (12)	5 (9)	24 (11)	
Educational level				0.39
< College	88 (56)	23 (42)	111 (53)	
College degree	48 (31)	21 (38)	69 (33)	
Advanced degree	20 (13)	11 (20)	31 (14)	
Marital status				0.91
Single	49 (31)	19 (35)	68 (32)	
Married/life partner	93 (60)	30 (55)	123 (58)	
Divorced	11 (7)	5 (9)	16 (8)	
Widowed	3 (2)	1 (2)	4 (2)	
Disease duration (years)				0.004
0–5	61 (39)*	33 (60)	94 (45)	
6–10	27 (17)*	13 (24)	40 (19)	
11–20	31 (20)*	5 (9)	36 (17)	
> 20	37 (24)*	4 (7)	41 (20)	
Currently in remission	88 (56)	31 (56)	119 (56)	0.99
Flare (past year)	68 (44)	29 (53)	97 (46)	0.26
Flare duration (weeks)				0.68
< 2	26 (17)	6 (11)	32 (15)	
2–6	32 (21)	11 (20)	43 (20)	
6–10	17 (11)	9 (16)	26 (12)	
10–20	16 (11)	4 (7)	20 (10)	
> 20	62 (40)	23 (42)	85 (40)	
Flare frequency				0.65
At least 1x/yr	94 (60)	34 (62)	128 (61)	

Characteristic, n (%)	CD (n=156)	UC (n=55)	Total Sample (N=211)	P
Once every 2–3 yrs	27 (17)	11 (20)	38 (18)	
Once every 4–5 yrs	14 (9)	2 (4)	16 (8)	
Once every 6–10 yrs	11 (7)	4 (7)	15 (7)	
Remission > 10 yrs	7 (5)	1 (2)	8 (4)	
Flare severity				0.68
Mild	24 (15)	8 (15)	32 (15)	
Moderate	54 (35)	23 (42)	77 (37)	
Severe	69 (44)	22 (40)	91 (43)	
Not sure	7 (5)	1 (2)	8 (4)	
Previous surgery	85 (55) *	3 (6)	88 (42)	0.000
# Surgeries				0.84
1–3	63 (74)	3 (100)	66 (75)	
4–5	13 (15)	0 (0)	13 (6)	
>5	9 (6)	0 (0)	9 (4)	
Ostomy	16 (10) *	0 (0)	16 (8)	.05
Extraintestinal symptoms	116 (75) *	29 (53)	145 (69)	0.004
Fistula	47 (30) *	5 (9)	52 (25)	0.002
Polysymptomatic	116 (74) *	29 (53)	145 (69)	0.002
Recruitment source CCFA	39 (25)	7 (13)	46 (22)	0.17
Online support	93 (60)	38 (69)	131 (62)	
Other online	24 (15)	10 (18)	34 (16)	

* $P \leq .05$.

TABLE 2

Descriptive Statistics for HRQOL, Psychological, and Stigma Scales

	CD (n=156)		UC (n=55)	
	Mean	SEM	Mean	SEM
HRQOL				
IBDQ total	163.1	2.90	167.6	5.67
IBDQ bowel symptoms	52.32	.89	52.91	1.81
IBDQ systemic symptoms	21.92*	.55	24.42	1.07
IBDQ emotional functioning	61.14	1.23	62.15	2.18
IBDQ social functioning	27.66	.65	28.11	1.20
Psychological				
BSI total	15.98	.94	14.82	1.59
BSI anxiety	4.6	.35	4.50	.56
BSI depression	6.14	.42	5.58	.69
BSI somatization	5.25	.32	4.75	.55
Self-esteem	21.12	.45	21.60	.81
Self-efficacy	31.90	.40	31.91	.76
Adherence				
MTBS total	.98	1.19	1.02	1.22
Stigma				
PSS-IBS	60.15	2.93	54.4	4.62
RFIPC body stigma	36.76	2.43	28.75	3.98

* $P \leq .05$.

TABLE 3

Reported Presence of Perceived Stigma

PSS-IBS Score	Mean ± SD	No Stigma n (%)	Low Stigma n(%)	Moderate Stigma n (%)	High Stigma n (%)
Total ^a	76.2 ± 45.6	33 (16)	114 (54)	89 (42)	8 (4)
Subscales ^b					
Family	11.6 ± 8.6	8 (4)	173 (82)	30 (14)	—
Friends	13.6 ± 8.7	10 (5)	152 (72)	49 (23)	—
Medical Providers	11.9 ± 10.3	42 (20)	125 (59)	43 (20)	1 (0)
Spouse	9.1 ± 9.3	40 (19)	148 (70)	23 (11)	—
Co-workers	13.6 ± 11.5	42 (20)	109 (52)	60 (28)	—
Employer	16.5 ± 11.3	21 (10)	123 (58)	67 (32)	—

^aScore out of 240. Low = 1–80, Moderate = 81–161, High ≥ 161.

^bScore out of 60. Low = 1–20, Moderate = 21–41, High > 41.

APPENDIX

Questions from Perceived Stigma Scale in IBS (modified for IBD)

-
- 1 My IBD symptoms are not taken seriously by...
 - ...My family members^a
 - ...My friends
 - ...My health care providers
 - ...My spouse/significant other
 - ...My co-workers/classmates
 - ...My boss/supervisor
 - 2 My IBD symptoms are believed to be more 'in my head' than physical by...
 - 3 I keep my IBD symptoms hidden from these people because they will treat me differently.
 - 4 My IBD symptoms are believed to be caused by something I'm doing or have done by...
 - 5 I do not feel I can be as open about my IBD symptoms as I'd like to be with...
 - 6 Some people do not have enough knowledge about IBD, including...
 - 7 Some people are not interested in hearing about my IBD symptoms, including...
 - 8 When some people know about my IBD symptoms, they treat me differently, including...
 - 9 Some people do not understand when I have to make changes to plans because of my IBD symptoms, including...
 - 10 I worry that the following people would pass me over or limit my opportunities if they knew I had IBD:
-

^aCategories are repeated under each question.